

Title: Development of a remote monitoring application to improve care and support patients in the first 30 days following colorectal cancer surgery

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Abstract

Objective: To design and develop a digital monitoring application to support and improve the care of patients in the first 30 post-operative days following colorectal cancer surgery.

Data Sources: Patient interviews, health professional focus groups, patient co-creation activities and health professional prioritisation discussions.

Conclusion: The structured and iterative co-design activities adopted in this study with key stakeholders, including patients and health professionals, lead to the development of a prototype app to support patients at home during the first 30 days following surgery for colorectal cancer. A similar approach could be implemented to develop comparable apps for patients with other cancer diagnoses requiring different surgical procedures. Further research should focus on the continued development and testing of this application in relation to patient care and outcomes as well as the app's impact on nursing and other health services.

Implications for Nursing Practice: Clinical implementation of remote monitoring following discharge home after surgery for colorectal cancer gives patients the opportunity to report issues of concern to relevant health professionals. This could facilitate the early identification of concerning signs and symptoms, ensuring appropriate and timely interventions to minimise readmission rates. Patients' experiences during the recovery period could also be improved through the provision of reliable and relevant online information. More specifically, health professionals could easily identify those patients requiring additional support to manage their recovery, for example, those with more severe symptoms or problems, facilitating the direction of appropriate health services to those most in need of their expertise.

Keywords: Colorectal cancer, surgery, remote monitoring, co-design, symptom management

Introduction

A growing number of clinical studies, research papers and consumer applications have utilised smart technologies to remotely monitor and support people with various health conditions in the home care setting. However, to date the predominant focus has been on the chronic management of long-term conditions, for example in elderly care ¹, diabetes ², hypertension ³ or multiple sclerosis ⁴, with less emphasis on monitoring people during the acute recovery phase following treatments, such as surgery.

Advanced surgical techniques and improved perioperative care have considerably lowered post-operative morbidity and mortality in patients undergoing gastrointestinal surgery. However, post-operative complications are more common following major gastroenterological surgery compared to other surgical specialities, resulting in increased resource utilisation ⁵. Unfortunately, major gastrointestinal surgery is accompanied by complication rates of up to 24% ⁶, with readmissions following initial discharge home caused by a variety of, potentially preventable, causes such as dehydration, ileus or obstruction and surgical site infections ^{7,8}. Such complications during recovery have the potential to reduce post-operative quality of life, delay further oncological treatment and impair the therapeutic outcomes of patients undergoing complex surgical procedures for cancer ⁹.

Enhanced recovery after surgery (ERAS) was developed to accelerate recovery and reduce length of hospital stay by mitigating the body's stress response and potential postoperative complications and mortality with the additional benefit of the reduction in associated healthcare costs ^{10,11}. However reducing the hospital stay both shortens the time during which health professionals can monitor patients closely as well as the time available to provide patient education. Ensuring early identification of complications and adverse events following discharge and so implementing timely and effective management in the home care setting, rather than costly readmission to hospital, is important to improve patient and healthcare outcomes. As such, digital health applications that promote early recognition of problems and post-discharge self-care are becoming increasingly appealing.

Objectives

To design and develop a digital remote monitoring application to support and improve the care of patients for the first 30 post-operative days following colorectal cancer surgery.

Specific research questions were:

1. What are the design requirements for the proposed system?
 - a. System content - e.g. what symptoms should be assessed, what information should be included?
 - b. System functions – e.g. how does the system promote self-care to patients, how does the system detect escalating symptoms early and how does the system alert health professionals of these and acute/emergency symptoms?
 - c. What do future users identify as the key benefits of such a system - e.g. improve patient symptom experience/ QoL, patient support and reassurance, reduce emergency readmission rates, reduce hospitalisation costs?
2. How usable is the prototype system specifically so, - by patients who have recently undergone surgery for colorectal cancer.

Methods

Study design

This study draws on the Medical Research Council's Framework for the development, evaluation and implementation of complex interventions to improve health¹² as it has several interacting components. It also utilised the Design Council's Double Diamond Model, a process that supports the implementation of participatory research and acknowledges that in all creative processes a number of possible ideas are created ('divergent thinking') before refining and narrowing down to the best idea ('convergent thinking'). This is represented by a diamond shape. However, the Double Diamond indicates that this happens twice – once to confirm the problem definition and once to create the solution¹³. Figure 1 maps the methods used in this study onto the Double Diamond process of design.

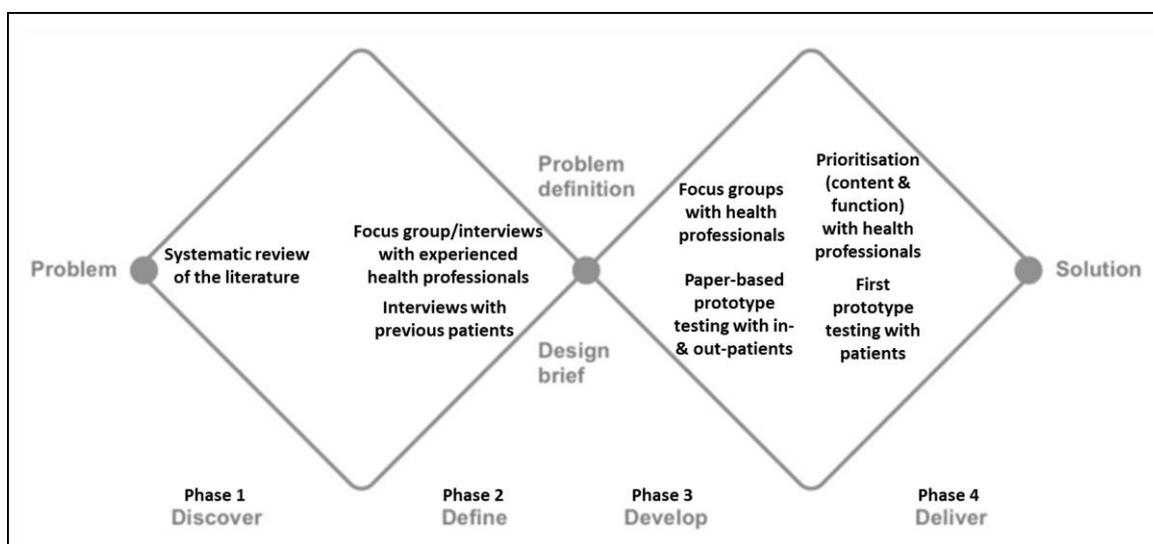


Figure 1: Study methods within Double Diamond Model

The study incorporated multiple user-centred methods throughout an iterative process that focused on users and their needs to develop a usable, meaningful and accessible remote monitoring app prototype by following the 2 sequential phases detailed below.

- (1) **Part 1 - Discover and Define:** Interviews and focus groups to identify patients' and health professionals' perspectives remote monitoring following colorectal cancer surgery, specific symptoms that should be assessed by in the remote monitoring app and design/presentation of user interfaces.
- (2) **Part 2 - Develop:** Interviews with patients and health professionals to evaluate their perceptions of a paper-based version of the app (as in-patients and following discharge home) and to explore the usability and general views of version 1.0 of the electronic app prototype by patients. Engage in a series of discussions with health professionals to prioritise the future content and functionality of the app.

Ethics: Ethical permission was granted by London – Fulham Research Ethics Committee (18/LO/0127) (part 1 of the study) and West of Scotland Research Ethics Committee 5 (18/WS/0086) (part 2 of the

study). The study received Research and Development Board Approval from Greater Glasgow & Clyde NHS (GN17ON693, GN18ON101). All participants provided informed written consent to participate.

Methods

Part 1: Identifying patients' and health professionals' perspectives of remote monitoring following colorectal cancer surgery, specific symptoms that should be assessed by in the remote monitoring app and design/presentation of user interfaces.

Members of the clinical team identified eligible patients who, with the patients' consent, passed their details to members of the research team. Following a standard process of informed consent, one-to-one semi-structured interviews were conducted with adult patients who had received surgery for colorectal cancer within the last year.

These interviews explored the following: patients' symptom experiences during their recovery after colorectal cancer surgery; any other important issues they had experienced as a consequence of their operation; their general perceptions about technology use in healthcare contexts; and their thoughts about the concept of remote monitoring using a digital application following surgery.

Experienced health professionals participated in focus groups/interviews to explore their perceptions of: patients' experiences following colorectal surgery; the function of remote monitoring for their patient population; and the feasibility of digital remote monitoring.

All interviews and focus groups were recorded and transcribed verbatim for thematic analysis. Thematic analysis was used to analyse the data. Thematic analysis is one of the most common forms of analysis within qualitative research and is a process for encoding qualitative information that focuses on capturing meaning and examining themes within the data. Because thematic analysis focuses on the subjective human experience, and emphasises the participants' perceptions, feelings and experiences as the object of study ¹⁴, it provided a particularly useful analytical approach for this piece of design work.

Part 2: Interviews with patients and health professionals to evaluate their perceptions of a paper-based version of the app (as in-patients and following discharge home) and to explore the usability and general views of the first electronic app prototype by patients. Prioritising the future content and functionality of the app with health professionals.

Incorporating all the information gathered in the discover and define phases, the study team developed a paper-based version of the remote monitoring app including content and presentation on user interfaces. Patients were recruited prior to their surgery for colorectal cancer and following informed consent, completed paper-based versions of the app (e.g. PROMs in random order) for 6 consecutive days following their surgery. During this time, patients took part in an interview whilst completing the questionnaire on the app and asked about the applicability and relevance of the paper based copy to their recovery, their ability to understand the questions and current and future app content and ways it could be improved. Patients were asked to comment on feature of the app indicating what ones they would like to keep, change or lose ¹⁵. Approximately 30 days post-op patients were interviewed again and asked to reflect on their recovery following surgery, and based on their experiences, give the perspectives on the future use of the app at this time. All interviews were recorded and transcribed

verbatim to facilitate analysis. Following this feedback, a low-medium fidelity prototype of the remote monitoring application was developed. Time constraints meant that it did not include all pages of the paper prototype and was not as interactive as originally intended however it addressed most features identified in previous phases as to enable user testing.

Following informed consent, patients who had recently undergone surgery for colorectal cancer participated in a 1-2-1 session with a member of the study team, during which the researcher used a 'think aloud' protocol ¹⁶ while the patient navigated the app on a mobile phone, and then a 'keep, change, lose' approach ¹⁵ following the app's completion. Patients were also asked for their opinions around the apps usability, applicability to their recovery experiences post-operatively, whether they would have been inclined to use the app had it been available to them as well as any other general thoughts. Responses were audio recorded to aid narrative/descriptive qualitative analysis.

A final workshop was held with a small group of experienced clinicians in colorectal surgery (half of whom had participated in earlier focus groups) to prioritise the content and functionality of the remote monitoring system. Although previous participation in the study may have had an impact on their views, their more in-depth understanding of the study could also have made their perceptions more reasoned. This prioritisation exercise was facilitated by a co-design process called the MoSCoW method. MoSCoW is an acronym derived from the first letter of each of the four prioritisation categories (**M**ust have, **S**hould have, **C**ould have, and **W**on't have) and is a technique previously used in management, business analysis, project management, and software development to reach a common understanding with stakeholders on the importance they place on the delivery of each requirement ¹⁷.

Results

Part 1: This phase of the study sought to identify patients' and health professionals' perspectives of patients' and health professionals' perspectives of remote monitoring following colorectal cancer surgery, specific symptoms that should be assessed by the remote monitoring app and design/presentation of user interfaces. A total of ten patients from a single clinical site participated in 1-1 interviews. Demographic data of participants are shown in Table 1.

Medical (n=5), nursing (n=3) and pharmacy (n=1) professionals from a single clinical site participated in focus groups/interview. They aged between 24 and 49 and had worked in the speciality between 7 months and 35 years (mean 12.8 years).

Patients and professionals identified similar symptoms and issues experienced during the post-operative period – both immediately post-operatively period (during hospitalisations) and following discharge home. Key symptoms such as pain and vomiting as well as issues around dietary intake and bowel/stoma management were highlighted. Fatigue and the emotional impact (highs and lows) of surgery were acknowledged by health professionals and reiterated by patients. Additional concerns such as financial and family worries were also identified as useful issues to be monitored. Both patients and clinicians felt the concept of remote monitoring was worthwhile. Key issues for inclusion in the remote monitoring application were identified and subsequently used to develop and inform the content of the future prototype – the first step of which was developing the paper prototype for use in Part 2. These key issues are detailed in Table 2 and demonstrates that some issues were identified by both patients and health professionals, while others were identified by one group or the other. Those identified by only health professionals tended to be of a more acute nature, problems that were likely to lead to readmission following discharge, while those identified by patients only were longer lasting,

non-acute and less 'visible' but nonetheless bothersome issues that had a significant impact on their return to their previous lifestyle.

Part 2: The aim of part 2 was to evaluate patient and professional's perceptions of a paper-based version of the application (as in-patients and following discharge home) and to explore the usability and general views of version 1.0 of electronic application prototype. This information was used to prioritise the future content and functionality of the application for subsequent development and testing.

Results of evaluation of paper prototype of the app: Eight patients from 2 clinical sites participated in the evaluation of the paper prototype. Demographic data for those patients are shown in Table 3. Medical (n=13) and nursing (n=2) professionals participated in 2 focus groups in 2 clinical sites. Health professionals were aged between 20 and 57 and had worked in the speciality between 3 months and 17 years (mean 8.7 years).

Table 4 compares patients' and clinicians' perspectives about the various sections of the paper-based prototype and their thoughts on how it could be translated into an electronic prototype. There were no major differences in opinions and perspectives relative to the prototype. Again, the health professionals saw the main function as alerting on the acute issues that result in readmission to hospital, and while they recognised the importance of assessing non-acute symptoms/psychological/social issues, they preferred that the app provide self-care information for such issues and symptoms to support patients without requiring direct intervention from the hospital team. Patients also saw huge benefits to having reputable information 'in a single space' rather than having to go through various channels for different information. Being able to personalise the app to the preferences of the user was important to patients. Health professionals expressed concern around the usability of the app by, for example, older patients or those who are less 'tech aware' however this issue was not raised by patients. This feedback was used to inform and develop a low-medium electronic prototype of the post op app.

Results of evaluation of electronic prototype of app: Seven patients from 2 clinical sites participated in this phase (see Table 5). Patients' perceptions in terms of user interface, acceptability, areas for development and their thoughts on the advantages of such an application are presented in Table 7. These perceptions show that the prototype app developed and tested in this phase of the study was clear, simple to use, acceptable and had definite advantages for patients during their recovery. Patients continued to want the app to be personalised for the individual, for example, in relation to presentation, frequency, specific topics included and options for responses from health professionals. The health professionals' prioritisation exercise identified that the top 4 priorities identified for app content were self-care, acute symptom assessment, assessment of emotional well-being and physical measurements while the top 4 priorities for app function were real-time monitoring, identification of acute symptoms, promotion of patient self-care and improving the patient experience/quality of life.

Discussion

This study developed a prototype app to support patients and improve care during the first 30 days following surgery for colorectal cancer. Importantly the development of the app was informed by qualitative co-creation interactions with patients and health professionals to identify key users' needs and preferences for the application. This paper provides a transparent account of the processes

undertaken to develop the prototype, facilitated by the Design Council's Double Diamond Model, demonstrating an example of a successful method through which to develop a digital health intervention.

There was relative consensus among patients and health professionals in terms of the most common symptoms and issues experienced in the first 30 days following surgery for colorectal cancer, including pain, nausea, bowel/stoma issues, emotional well-being, eating problems and fatigue. These results confirm existing knowledge about commonly experienced symptoms and issues following colorectal surgery ^{7,8,18}. However it is also important to note the disparity between patients and health professionals in relation to some of the symptoms and issues that each group felt should be included in the app, with health professionals focussing on the acute symptoms seen on readmission following surgery while patients identified the longer-term, less visible issues that they had experienced at home. It could be that using an app such as this would help health professionals better understand the lived experience of symptoms and issues that patients cope with following discharge and that could be impacting on their quality of life ¹⁹.

Health professionals saw the provision of self-care information as a key function of this app and patients expressed positive attitudes towards such information being included in the app. Although advances in medical practice such as the 'Enhanced Recovery After Surgery' (ERAS) programme, as well as minimally invasive surgical techniques have had positive effects on morbidity ²⁰ and shorter hospital stays ²¹⁻²³, this minimises the opportunities for information giving and patient education. It has also been suggested that traditional follow-up does not always address patients' psycho-social and information needs in relation to providing information tailored to individual need as well as being responsive to urgent patient concerns ²⁴. Indeed, the need for specific, tailored information was identified as a potential reason for the failure of a standardised nurse-delivered telephone-based service to improve care co-ordination and patient reported outcomes following surgery for colorectal cancer ²⁵. Patients have also reported using information within an app as a second opinion, being more likely to follow advice that is authoritative ²⁶. Using the app developed in this study could address these issues, providing patient access to reliable self-care information, targeted to their particular needs while also alerting the relevant health professional of their more urgent concerns.

It is also important to highlight the discrepancies between what patients say and what patients do. Patients in this study were generally very positive about the usefulness of the app, seeing it as a tool that could benefit them during their post-operative recovery period. Most said they would have used it had it been available following their surgery. However, such positive attitudes should not be assumed to translate into practice. In a previous study of a post-operative app to facilitate communication post-surgery, patients were able to use the app and believed it to be easy to use but, in practice, there was sub-optimal patient engagement ²⁶. Previous research has shown that apps designed to improve the management of complications at home need to enhance patients' knowledge, self-efficacy and communication ²⁷ while being accessible, usable, secure, patient-centred, facilitate communication and personalised management ²⁸. We believe that the prototype app developed in this study would address these issues. Discrepancies have also been shown between patients regarding other functions of apps, such as the camera function. While the majority of patients in our study said they could see the advantages of having a camera function in the app and would use it, other research has shown that patients are unwilling or unable to use such a function, even when they had previously stated otherwise ²⁶.

Our prototype app did not include any objective measures. However functional status is an important aspect of surgical care and physical and functional limitations are common after major abdominal surgery ^{29,30}. Real-time location systems have been used in the in-patient setting to track post-operative

patient mobilisation³¹ while combining wristband pedometers with online patient reported outcomes has been shown to be feasible as well as having potential to identify high-risk populations requiring additional interventions to support post-operative functional and symptom recovery^{32,33}. The health professionals in our study did identify wearable outcome measures as a potentially useful addition for future apps, identifying increased heart rate and temperature as key measures that would be helpful in clinical assessments.

It has been suggested that the degree of concern felt by patients with regards to the potential outcomes of their condition may influence how well they interact with such apps²⁶. Given their oncological diagnosis, this could explain our populations' positive attitudes towards the app in this study. The health professionals in our study were also positive about the use of the app, though were keen to clarify its primary aim. For example, was the app to focus on physical outcomes, such as reduced readmission rates, or rather improved patient experiences and quality of life, for example through increased information and support? They expressed concern about workload due to alerts or increased phone traffic as well as the ability of the system to direct alerts to the most appropriate healthcare service/personnel. Similar workload concerns were raised in a study to track patients after GI surgery, however each patient generated only 1.1 alerts over 30 days, limiting burden to the staff, while potential benefits included reduced length of stay and improved patient satisfaction with the recovery process³³. Understanding the experiences of previous studies might mitigate our health professionals' concerns. Finally, the current COVID-19 pandemic, while presenting so many challenges, highlights the importance of well-designed, usable digital systems to remotely support people following surgery and it is anticipated that all potential users, patients and health professionals alike, will be more motivated than ever to engage with such opportunities.

Challenges encountered

Patient recruitment was challenging. Across all phases of the study, the research team were reliant on already busy health professionals to identify eligible patients. Although willing to take on this task, it was in addition to their existing clinical practice. Interactions with patients were already packed with information provision around important issues concerning diagnosis, proposed surgery and recovery so providing additional information about the study was not always possible or appropriate. This, combined with a relatively small potential population, reduced the number of patients approached to participate. This demonstrates some of the real-life challenges of conducting research in today's health service. Patient recruitment targets were met by around just 50% across all phase of the study. That said, the enthusiasm of those patients who did participate and the richness of the data that they provided allows the research team to be satisfied that the information collected across phases 2, 3 and 4 of the study was consistent in content. Additional collection would most likely have resulted in reiteration of the information gathered.

It had been our intention to work with groups of patients, holding workshops and focus groups rather than individual patient interactions. However, the practicalities of the situation (i.e. trying to gather a number of post-operative patients in a single place at a set time, with the incumbent travel and time costs for patients) meant that this was not achieved. On reflection, being unable to hold groups may have had benefits for the data we were able to gather, as discussing post-operative experiences often included sensitive topics that some people may have found difficult to share in a group setting. Also many patients were still in the immediate post-op recovery phase making travel more difficult for them and so participating in the comfort of their own home was more practical and likely to elicit open and

honest communication about their recovery and individual perspectives on the system being developed.

Study Strengths

A key strength of this study's development process was the prioritisation of the user-centred methodology, with its bottom up approach to developing the content and functionality of the electronic prototype. We defined co-design in this study as an iterative process of developing a product (digital prototype app) with its intended end users i.e. both patients and clinicians working closely with members of the study team. Representatives of these end users were involved in all parts of the study, ensuring that the content and functions of the final prototype was as acceptable and appropriate as possible, but also have giving clear direction for future developmental studies of the app.

Study Limitations

The study has 3 main limitations. Firstly, the use of a more structured method of assessing usability, such as the System Usability Scale ³⁴ (a brief questionnaire with 5 responses ranging from strongly agree to strongly disagree) (Scott et al), would have added reliability to the patient evaluation of the app. Further development and evaluation activities associated to this application will incorporate such a measure.

Secondly, the transition from the paper prototype to the electronic prototype was time limited. As such, some features from the paper version did not make it into the electronic version. While the missing features (assessment of physical function, the distress thermometer and self-care information) were described to patients participating in this phase, we acknowledge this is not the same as them being included in the electronic prototype. Nevertheless, all reports around the user-interface and -acceptance testing were positive irrespective of whether they were present in the electronic prototype and future research will include these aspects.

Finally, the prioritisation exercise (of app content and function) conducted with health professionals during part 2 would have been more complete had patients' priorities also been explored. This would have allowed for a comparison between the two populations and given direction for future studies. Unfortunately, time constraints, as well as the aforementioned difficulties in organising groups of patients, meant that this was not possible within the confines of the current study. However, the first step of future research will involve exploring patients' priorities around content and function.

Recommendations for future research

Further development and exploration of a remote monitoring app to support patients in the first 30 days following surgery for colorectal cancer is warranted based on the results of this study. Using the MRC Complex Intervention Framework ¹², the next phase would fully develop the app in relation to the key components identified by patients and clinicians in this study and go onto explore its feasibility and acceptability to all users.

Clarity around the main aims of the future app would be important. While we expect such an application could improve patients' experiences and sense of support during their recovery period including longer lasting, 'invisible' and bothersome issues, it may also be able to reduce/prevent readmission to hospital through the early detection of early/acute complications and so lessen costs. It is to be hoped that these aims are not mutually exclusive, and this app could positively impact on both.

Irrespective of aims, results of this study point to key aspects of the future app including:

1. Personalising and tailoring – patients wanted an app to be personal, specifically around their clinical details, social situation, personal preferences for completion, literacy, technical abilities. A tailoring facility to allow the app to meet the needs of the individual (and that may change over time) is a key component of future research. Adding objective measures (such as heart rate monitors, activity trackers) would allow for additional outcome data to be gathered with minimal effort from the patient.
2. Assessment of symptoms (with appropriate clinical action) – patients and clinicians recognised the important function of the app in providing access to clinical advice for key symptoms of concern. This should be a key element in subsequent app developments.
3. Provision of information - patients consistently wanted information provided through the app – while information is a core component of the care delivered in hospital, patients reported feeling overwhelmed and struggled to remember all the information, with the potential for negative outcomes. An app that gathers all relevant information in one place, from trusted sources with links to reputable websites, would be helpful.

Conclusions

This paper provides a detailed example of the development and design process of a digital remote monitoring application to support patients in the first 30 days following surgery for colorectal cancer. The methods undertaken and the lessons learnt are applicable to the design of other such digital interventions, indeed there is significant potential for remotely monitoring patients following a range of surgical procedures across a variety of specialities. Further development and testing of this remote monitoring app is required, not only to explore its potential for patients but also its effectiveness and impact on health services.

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Tables

| Gender | | Age | | Marital status | | Home situation | | Ethnicity | | Qualifications | | Work | |
|--------|---|-------|---|----------------|---|--------------------|---|---------------|---|----------------|---|-----------------|---|
| Male | 4 | 40-50 | 1 | Married | 6 | Lives alone | 4 | Scottish | 7 | None | 6 | Full-time | 2 |
| Female | 6 | 51-60 | 1 | Widowed | 3 | Lives with 1 other | 3 | Other British | 3 | School | 2 | Part-time | 2 |
| | | 61-70 | 3 | Single | 1 | >3 in house | 3 | | | Professional | 2 | Retired | 5 |
| | | 71-80 | 3 | | | | | | | University | 1 | Disabled/unable | 1 |
| | | 80+ | 2 | | | | | | | | | | |

Table 1: Part 1 Patient Demographic Data

| Patient & health professionals | Patient only | Health professional only |
|--|---|---|
| Pain – immediate & longer term | Fatigue – longer term, difficulty performing daily activities | Increasing pain |
| Fatigue – immediately post-op | Continued poor appetite | Dehydration associated with stoma output |
| Post-operative nausea | | Signs of infection, fever, sweats, wound redness/oozing etc |
| Issues around eating and drinking | | Gastrointestinal issues - diarrhoea, no bowel movements and stopping passing flatus, not able to eat, |
| Bowel/stoma issues | | |
| Emotional highs and lows following surgery and discharge | | |

Table 2: Symptoms/issues identified as important for inclusion in future prototype design

| Gender | | Age | | Marital status | | Home situation | | Ethnicity | | Qualifications | | Work | |
|--------|---|-------|---|----------------|---|--------------------|---|---------------|---|----------------|---|-----------------|---|
| Male | 5 | 30-40 | 1 | Married | 5 | Lives alone | 3 | Scottish | 8 | None | 1 | Full-time | 5 |
| Female | 3 | 50-60 | 4 | Widowed | 1 | Lives with 1 other | 4 | Other British | 0 | School | 3 | Part-time | 1 |
| | | 60-70 | 1 | Single | 2 | >3 in house | 1 | | | Professional | 1 | Retired | 2 |
| | | 80+ | 2 | | | | | | | University | 3 | Disabled/unable | 0 |

Table 3: Part 2 – Paper Prototype Patient Demographic Data

| Paper-based prototype | Patient perspectives | Clinician perspectives |
|-----------------------|---|--|
| Physical Symptoms | <p>All questions relevant and understandable</p> <p>Individual preferences around timing and frequency of assessments</p> <p>Presentation - no specific preferences re presentation</p> <p>Ordering - best to have most acute symptoms first incase questionnaire unfinished</p> <p>Adding question re blood clots might be helpful</p> <p>Option for 'any other symptoms' is useful</p> <p>Honesty important when completing the questionnaire</p> | <p>Preference to focus on assessment of acute symptoms that lead to re-admission</p> <ul style="list-style-type: none"> - stoma output/volume - dehydration - wound care/infection - urine retention <p>For non-acute symptoms – use system to promote self-care and patient empowerment, clinician could also use these details as background information</p> |
| Emotional issues | <p>Consequences of a stoma would be emotional</p> <p>Important to assess as some people at very low ebb and can be difficult to stay positive (especially depending on diagnosis)</p> <p>Frequency – not daily, once or twice a week - might be helpful for seeing changes over time</p> | <p>Advantageous to consultations if clinicians understand how the patient has been feeling emotionally</p> |
| Social issues | <p>Important to include</p> <p>More relevant to some people than others</p> <p>Dependent on personal circumstances</p> <p>Report would show functional improvement</p> | <p>Can see the advantage of understanding the patient experiences but would not want to be included in alerts</p> |
| Functionality | <p><u>Self-Care Information</u></p> <p>Definitely useful - best to personalise for the individual's symptom experiences.</p> | <p><u>Self-Care Information</u></p> <p>Could use the system to promote self-care/empower patients for non-acute symptom management</p> |

| | | |
|--------------------|--|--|
| | <p>Advantageous to have all information ‘in one place’ as information overload during hospitalisation.</p> <p>Text format of information preferred (n=4) though acknowledge audio good for those who struggle with reading.</p> <p>Consistency in presentation format (all text, audio, video)</p> <p>Contact details for the clinical team would be helpful.</p> <p><u>Camera</u> Definite aid for communication (n=5). Could be awkward to physically take the picture.</p> <p><u>Other helpful information</u> Having links/signposts to other helpful and <u>reputable</u> services would be excellent The more information available the better – save contacting the hospital => reduce pressure on health services. Keep it simplistic – population will vary in levels of education/literacy etc</p> <p><u>Feedback Reports/Graphs</u> Helpful to visualize improvements in recovery Diary function detailing progress e.g mobility, walking, housework</p> | <p><u>Camera</u> Would be a helpful function – patients already share photos with clinicians. Unsure of ethical implications of cameras in a study.</p> <p><u>Other helpful information</u> Potential to link to wearable technology – HR, temperature</p> <p><u>Feedback Reports/Graphs</u> Weekly summaries would be more helpful for patients than clinicians Targets might be helpful for some patients (e.g. fluid intake, steps) Both patients and clinicians should be able to view/respond on mobile technology – own phone preferable</p> |
| Alerting functions | <p><u>Issue for alert</u> Fantastic to be able to ‘flag’ potential problems to relevant professionals</p> <p><u>Communication – mode, timing</u> Personal preferences for communication following alerts – text or phone call both acceptable. Also dependent on what the issue is and how concerned the patient feels about it. A text message means less worry about missing a call. Varied preferences re response times</p> | <p><u>Issue for alert</u> Needs to have clear clinical benefit - can see benefits in identifying patients in need of support</p> <p><u>Communication – mode, timing</u> Concerns over associated workload – increased phone traffic – should reduce rather than add to workload.</p> |

| | | |
|--------------------|---|--|
| | <p>Potential for an 'emergency' type function.</p> <p><u>Personnel preferences</u> Best to speak to a professional who is a specialist for your problem (colorectal, stoma) – have trust in the person – more difficult to get in touch out-of-hours</p> | <p><u>Personnel preferences</u> Concerns - who is best to respond to alerts? Potential to link with community services and joined up care is best option e.g. linking with GPs would be beneficial to prevent unnecessary workload for acute services</p> |
| Issues to consider | <p>Individuality – could the app be 'personalised' for the individual as everyone is different</p> <p>Using the app would be useful even when recovery is uneventful as it would be reassuring and reassurance is key to recovery.</p> <p>Sense that technology shouldn't completely replace 'human' contact</p> <p>Could the app provide access to out-of-hours services e.g. specialist nurses, stoma nurse</p> | <p>Potential for elderly/low socioeconomic groups to have difficulty with technology? Should this be used for all patients or specific at-risk groups?</p> <p>Need a clear aim for future app – e.g. reduce symptom severity/acute admissions or improve patient experience/QoL. Concerns that using the app could increase anxiety through focusing too much on specific symptoms</p> <p>Concerns around over-reliance on technology</p> <p>Optimal period of time for using such an app – current lack of information about extended recovery?</p> |

Table 4: Comparison of patients' and health professionals' perspectives of paper-based app and its translation into electronic format

| Gender | | Age | | Marital status | | Home situation | | Ethnicity | | Qualifications | | Work | |
|--------|---|-------|---|----------------|---|--------------------|---|---------------|---|----------------|---|-----------|---|
| Male | 5 | 50–60 | 1 | Married | 3 | Lives alone | 3 | Scottish | 7 | None | 5 | Full-time | 3 |
| Female | 2 | 60-70 | 5 | Widowed | 1 | Lives with 1 other | 2 | Other British | 0 | School | 0 | Part-time | 1 |
| | | 70-80 | 1 | Single | 1 | >3 in house | 2 | | | Professional | 1 | Retired | 3 |

| | | | | | | | | | | |
|--|--|--------------|---|--|--|--|------------|---|-----------------|---|
| | | Sep/divorced | 2 | | | | University | 2 | Disabled/unable | 0 |
| | | | | | | | | | | |

Table 5: Part 2 – Electronic Prototype Patient Demographic Data

| | |
|--------------------------------|--|
| User interface design | <ul style="list-style-type: none"> • What about people who are colour-blind – red/green are issues • Simple/clear to use • Could add a reminder of timeframe being assessed • Written information preferred |
| Acceptance | <ul style="list-style-type: none"> • Should be made relevant to individual e.g. don't ask about childcare if you don't have children, accommodate for deaf, eye problems, literacy, translation • More detail for stoma questions are necessary – can be difficult to adjust to a stoma, pre-op felt that that 'death would have been preferable', can be difficult to make contact with stoma services –out-of-hours can be an issue • Relevant to experiences of recovery (physical and emotional) – reassuring • Would have used this system during recovery if given the option • Wouldn't feel initially able to/want to complete the app when discharged (as feeling too unwell/fatigued) |
| Areas for Future Consideration | <ul style="list-style-type: none"> • Alert responses - Only worth having alert function if someone dedicated to deal with alerts and responds quickly (e.g. 24hr helpline) – depends on how serious the issue is – response should be within the day – answer rather than medium is more important – nurses would be ideal for dealing with alerts – practice nurse would be 'handy' – individuality in preference, so just ask • Social/emotional/financial issues reported should also be followed-up • Frequency – individual - daily, weekly, try to get back to normal rather than a constant reminder • Camera function – welcomed (in the main) • Would have been useful pre-operatively to provide information • Could include issues around body image • Video exemplar of people who have had similar operations living full lives would be helpful – promoting a positive outlook, life after the operation, reassurance |
| Advantages | <ul style="list-style-type: none"> • Facilitates the decision making process - for people that don't want to unnecessarily 'bother' health professionals, differentiate urgent issues from those less urgent • Save time for health professionals • Reduce the number of people having to come into hospital • Good to see technology being a force for good • Reduces fear of isolation from hospital during recovery • Could be used across many different specialties |

Table 7: Electronic prototype Patient Perspectives